



#### Let's Talk: Clinical Trial Readiness & Community Preparation

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Visit <u>kif1a.org/2019Conference</u> to watch a recording of this presentation.



# Our role in R&D



### What is R&D?

## Research & Development

## WE ARE THE "AND" IN R&D



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Columbia University DEPARTMENT OF PEDIATRICS

College of Physicians and Surgeons



And other KIF1A researchers / Collaborators





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Who's going to step up?

**Biotech / Industry?** 

**Individuals?** 

**Translational Researchers?** 



### How we Accelerate R&D: Our Jobs

**Be proactive with your data and your story:** *Trust the Foundation. Trust the Chung Lab.* 

Be active in the rare disease community: Remember, being present is active.

**Be contactable:** We can't expect urgency if we don't respond with urgency.

**Take video:** What matters most? If we can't capture it, we can't fix it.

**Get Zoom:** We're global. We're strong. We can meet real-time. One mission, one foundation.

**Be relentless:** In your love for our children, for our community, for our science and for yourself.



Weekly Jobs: Every week we'll email you a job

#### **Our Job Next Week**

- Email every biotech with a neuroscience program and tell them we need their help today. Challenge them to "think rare." The science and technology exists.
- Monday each KIF1A family will receive a list of email addresses and contact information for every biotech and an example message.